

KATHLEEN O'SULLIVAN-FORTIN, ESQ.

EXPERIENCE

ALD CONNECT, INC., Middleton, MA

Founding Board of Directors Member, 2013-present; Patient Advocate, 2013-present; Treasurer, 2013-present; General Counsel, 2021-present.

Established a 501(c)(3) non-profit organization where patients, physicians, and researchers are equal stakeholders working together to advance a cure for Adrenoleukodystrophy (ALD) and to support patients with ALD. Managed PCORI Phase 1 PPRN-CDRN project to completion, served on Steering Committee. Drafted organizational bylaws and policies, assisted in creation and administration of patient outreach programs (monthly support calls, Peer Mentor Program, Direct Patient Support Grants, educational webinar series, SCOUT program, WG4/Patient Outreach & Education, etc.). Founding member of successful Industry Advisory Counsel (IAC) with quarterly meetings of pharmaceutical company representatives discussing potential collaborative ALD efforts. Plan and host annual scientific and community meetings and Bootcamps, with up to 500 attendees. Represent ALD Connect at numerous US and International Leukodystrophy/Rare Disease meetings/organizations/committees. Responsible for management of all assets, resolution of all conflicts and expenses, drafting and review of all agreements to which ALD Connect is a party. Negotiated and executed Asset Transfer Agreement between the Myelin Project and ALD Connect whereby the former Myelin Project effectively merged into ALD Connect in 2019. Vetted and hired ALD Connect's first (and current) Executive Director. Dedicated to amplifying the patient voice through creation of industry focus groups, assisting in planning and execution of FDA Listening Session, and sharing personal ALD Patient Impact Story as a motivational speaker.

CORPORATE LEGAL PARTNERS, LLC, Topsfield, MA

Consultant, 2012-2015

Assist clients with bankruptcy-related business issues. Draft bankruptcy claims and correspondence. Evaluate strength of 11 u.s.c section 547(c) preference actions. Assist client in general contract resolution matters.

ZONING BOARD OF APPEALS, Boxford, MA

Alternate Member, 2005-2015

Participated in monthly meetings for town Board of Appeals issuing special permits and variances; evaluated written and oral testimony on a range of zoning issues. Drafted formal opinions of Zoning Board of Appeals decisions

WILMER HALE, LLP, Boston, MA

Associate, 2001-2004; Legal Intern, Summer 2000

Specialized in commercial loan documentation and bankruptcy proceedings. Negotiated and settled Preference actions, drafted bankruptcy pleadings, negotiated terms of commercial loans, managed the securitization of commercial loans, and maintained client compliance with commercial loan covenants. Managed Pro Bono caseload of general litigation matters.

LARE TRAINING CENTER, Chelsea, MA

Counselor, 1997-1998

Maintained caseload of 25+ (former and current) teen mothers and at-risk youth in Welfare-to-Work GED program. Counseled students on educational and career action plans. Instructed classes on life skills including financial responsibility, parenting, and health concerns.

EDUCATION

HARVARD UNIVERSITY LAW SCHOOL, Cambridge, MA
Visiting Scholar, 2000-2001 academic year

UNIVERSITY OF PENNSYLVANIA LAW SCHOOL, Philadelphia, PA
Juris Doctor, 2001
Associate Editor, *Journal of Constitutional Law*

COLLEGE OF THE HOLY CROSS, Worcester, MA
B.A. Chemistry, 1996
Concentration in Chinese Language

OTHER THINGS TO KNOW ABOUT ME

- ALD Patient, mother of three children, one of whom has ALD
- 2020 ALD Connect Ambassador of the Year
- 2019 CPSA Analytics Solutions for the Patient Bowling Pin
- 2015 Global Genes RARE Champion of Hope Award for Collaborations in Science
- ALD Family Weekend Planning Committee (2019-present)
- NIH Rare Disease Clinical Research Network (RDCRN) CPAG Committee Member (2019-present)
- United Leukodystrophy Foundation (ULF) PAG Program Patient Registry Committee Member (2021-present)
- IndoUSrare Patient Alliance Member (2021-present)
- EveryLife Foundation Rare Disease Legislative Advocates (RDLA) Program Member (2018-present)
- Alliance of Regenerative Medicine (ARM) Patient Advocacy Committee Member (2019-present)
- Admitted to the practice of law in all courts in Massachusetts and the Federal Courts of the First Circuit (2001-present)
- 200 hr. RYT certified Yoga Instructor (2016-present)